

CAREGIVERS BURDEN REGARDING HOMECARE OF INTELLECTUAL DISABILITY IN CHILDREN AMONG PRIMARY CAREGIVERS IN A SELECTED SPECIAL SCHOOL AT TIRUNELVELI DISTRICT

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ABSTRACT

Introduction: Intellectual disability can be defined as a significant limitation in both intellectual functioning and behaviour, which refers to general mental disabilities, such as in learning, problem solving, interpersonal skills, social responsibility, daily activities and practical skills [AAIDD, 2013]. Basic functions of caregivers are to meet the physical and health needs of a child suffering from intellectual disability. Giving daily care to a child with intellectual disability can be a burden for primary caregivers. The burden associated with rearing a child with intellectual disability has manifold problems like disturbance of routine, family leisure, family health, drain on time, physical and emotional energy as well as financial resources of the caregivers. When primary caregivers gain information about the condition of the child, they become better equipped to understand how to deal with the child and it will reduce their burden level regarding homecare of children with intellectual disability.

Materials and Methods A true experimental research design of pre- and post-test with control group was adopted for the present study. Simple random sampling technique was used to allocate the groups as experimental and control group (N=60+60=120). The researcher developed the family burden interview schedule (FBIS) and a structured teaching module. For validity and reliability, it was found valid (cvr=1) and reliable (r=0.92). After pre-test the structured teaching module was administered to the experimental group whereas control group did not receive any intervention. After a month's interval post-tests were conducted consequently using the same tool as per schedule.

Results: Descriptive and inferential statistics were computed. In the experimental group caregivers' burden scores had consequently reduced. ANOVA and Bonferroni were computed since it had repeated measures. The mean score of caregivers' burden in the experimental group was statistically significant ($p < 0.05$) whereas in control group knowledge scores were found not insignificant.

Conclusion: Considering the results, structured teaching module was found effective in reducing caregiver's burden of primary caregivers of children with intellectual disability.

KEYWORDS: Effectiveness, Structured teaching module, children with Intellectual disability, Primary caregivers, Caregiver's burden.

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INTRODUCTION

Welcoming the newborn baby is a great excitement with expectations of joy and happiness for the family. This expectation may become shattered with the birth of an intellectually disabled child. Having an intellectually disabled child born in a family and grow into adulthood is one of the most stressful experiences a family can endure. Intellectual disability may be one of the most difficult conditions for primary care givers to accept. Worldwide, approximately 156 million people, or 3% of the world's population are intellectually disabled (WHO, 2013). Census of India (2011) revealed that, 6% or 1.2 million people are intellectually disabled. It is estimated that 1,00,847 persons in Tamilnadu State, and 5195 persons in Tirunelveli District alone had intellectually disabled children.

Aim of the present study was to evaluate the effectiveness of the structured teaching module for primary caregivers regarding homecare of children with intellectual disability. Burden means, the presence of problems, difficulties or adverse effect that happens in the lives of significant others. Intellectually disabled children will most likely not be able to grow up to realise their caregivers' dreams and expectations. The primary caregivers of children with intellectual disability require lifelong adjustments. Hence the primary caregivers need guidance through a teaching module which is an important aspect of management. Home is the vital place of care for an intellectually disabled child. The child may be dependent on the primary caregiver's help throughout his or her life. Care giving is a natural aspect of primary caregivers who need to help the child twenty-four hours a day with basic tasks such as feeding, dressing, hygiene etc. While primary caregivers describe the positive benefits that the child with intellectual disability brings to their lives, the care of these children can have a significant impact on the family, the home and on the physical, emotional and mental health of the primary caregivers.

METHODOLOGY

True experimental research design for the study population comprised experimental group (60) and control group (60). Simple random sampling technique was used to draw the samples from selected special schools at Tirunelveli District. The tools used for the study were: Part I - Demographic variables, Part II - Family burden interview schedule (FBIS) regarding homecare of intellectually disabled children. This study was approved by the research development committee members from Himalayan University, Itanagar in Arunachal Pradesh. Formal permission was obtained from the Annai Jothi Seva Trust, Adayakarungulam, and Anbu illam, Cheranmahadevi, Tirunelveli District. The caregiver's burden of primary caregivers was assessed using pre-test family burden interview schedule. After the pre-test was done, structured teaching module was given to the experimental group consisting of 60 primary caregivers of children with intellectual disability and was discussed. After a gap of a month the post-test was carried out consequently three times on the primary caregivers with the same tool and structured teaching module.

FINDINGS AND INTERPRETATIONS

Descriptive statistics (mean and SD) and inferential statistics (ANOVA and Bonferonni) were computed for analysing the results by using SPSS software, version 16.

Description of demographic data: In the experimental group, highest percentage (70%) of the caregivers were in the age group of 31 and above, were Hindus (65%), had higher secondary schooling (40%), were homemakers (96.7%), had income of 5001-10000 (81.7%), parents had consanguineous marriages (83.3%), mothers as primary caregivers (98.3%), male child (98.3%), 11-15 years old children (50%), first child (93.3%), disability recognised below one year (96.7%), moderate level of intellectual disability (76.7%), causes of disability being genetic (95%), child had autism (68.3%), no previous knowledge regarding homecare of intellectual disability (88.3%).

In the control group, the highest percentage (83.3%) of the caregivers were in the age group of 31 and above, were Hindus (53.3%), had primary schooling (50%), were homemakers (100%), had income 5001-10000 (83.3%), parents had consanguineous marriages (80%), mothers as primary caregivers (95%), male child (91.7%), 6-10 years old children (73.3%), first child (98.3%), disability recognized below one year (91.7%), moderate level of intellectual disability (66.7%), causes of disability being genetic (91.7%), child had autism (61.6%), no previous knowledge regarding homecare of intellectual disability (93.3%).

Table 1: Frequency and percentage distribution of primary care givers according to their Demographic data

Sl. No.	Demographic data		Control group		Experimental group	
	Primary caregivers detail		frequency	Percentage	frequency	Percentage
1.	Age of caregiver (in years):	20-25	1	1.60	0	0
		26-30	9	15.00	18	30.00
		31 and above	50	83.30	42	70.00
2.	Religion	Christian	21	35.00	17	28.30
		Muslim	7	11.60	4	6.67
		Hindu	32	53.30	39	65.00
		Others	0	0	0	0
3.	Educational status	Illiterate	10	16.70	6	10.00
		Primary school	30	50.00	18	30.00
		Higher secondary school	20	33.30	24	40.00
		Graduate and above	0	0	12	20.00
4.	Occupation:	Government employee	0	0	0	0
		Private sector	0	0	2	3.30
		Home maker	60	100.00	58	96.70
5.	Income	Below Rs5000	9	15.00	0	0
		Rs.5001-10000	50	83.30	49	81.70
		Above 10000	1	1.67	11	18.30
6.	Type of marriage:	Consanguineous marriage	48	80.00	50	83.30
		Non consanguineous marriage	12	20.00	10	16.70
7.	Relationship with the child	Mother	57	95.00	59	98.30
		Father	3	5.00	1	1.70
		Others	0	0	0	0
	Child's detail					
8.	Sex of the child	Male	55	91.70	59	98.30
		Female	5	8.30	1	1.70
9.	Age of the child	1 - 5 years	1	1.60	4	6.67
		6 - 10 years	44	73.30	26	43.30
		11 - 15 years	15	25.00	30	50.00
10.	Position of the child with in the family	First child	59	98.30	56	93.30
		Second child	1	1.70	4	6.70
		Last child	0	0	0	0
11.	Age in which the disability was first recognized	Below 1 year	55	91.70	58	96.70
		Above 1 year	5	8.30	2	3.30
12.	Level of intellectual disability	Mild	16	26.70	9	15.00
		Moderate	40	66.70	46	76.70
		Severe	3	5.00	2	3.30
		Profound	1	1.70	3	5.00
13.	Cause of disability	Genetic	55	91.70	57	95.00
		Others	5	8.30	3	5.00

14.	Other type of disability existing	Blind	10	16.70	3	5.00
		Deaf and dumb	10	16.70	6	10.00
		Autism	37	61.60	41	68.30
		Others	3	5.00	10	16.70
15.	Previous knowledge about homecare of intellectual disability	Yes	4	6.70	7	11.70
		No	56	93.30	53	88.30
16.	Previous knowledge about homecare of intellectual disability children	Mass media	2	3.30	0	0
		Special school	2	3.30	7	11.70
		Health personnel	0	0	0	0
		No information	56	93.30	53	88.30

Table 2: Comparison of pre and post tests caregiver's burden scores before and after implementation of STM

N = 60 + 60 = 120

Level of burden	Control group								Experimental group							
	Pre-test		Post-test 1		Post-test 2		Post-test 3		Pre-test		Post-test-1		Post-test-2		Post-test-3	
	f	%	F	%	f	%	f	%	F	%	f	%	f	%	F	%
Severe burden	42	70	41	68.3	41	68.3	40	66.7	44	73.3	1	1.7	2	3.3	1	1.7
Moderate	18	30	19	31.7	19	31.7	20	33.3	15	25.0	32	53.3	23	38.3	21	35.0
No burden	0	0	0	0	0	0	0	0	1	1.7	27	45.0	35	58.3	38	63.3
Total	60	100	60	100.0	60	100	60	100.0	60	100.0	60	100.0	60	100	60	100.0

Table - 2 depicts that in the pre-test control group, 70% had severe caregivers burden. In the experimental group, the pre-test showed 73.3% had severe burden; in post-test-1, it showed 53.3% had moderate burden; and in post-test-2 and post-test-3 it showed 58.3%, 63.3% respectively had no burden.

Table - 3: ANOVA for repeated measure of caregiver's burden scores of experimental and control groups to assess the effectiveness of STM on home care of children with intellectual disability among primary caregivers

N=(60+60=120)

Group	Experimental group				Control group			
	Mean	SD	F-Value	P-value	Mean	SD	F-Value	P-Value
Pre-test	37.57	10.620	383.12	P<0.001***	39.12	10.61	16.68	0.001**
Post-test I	61.18	6.758			40.20	10.07		
Post-test II	62.50	6.560			40.52	9.97		
Post-test III	63.00	6.874			40.80	10.05		

*-P<0.05, significant and **-P<0.01 & ***-P<0.001, highly significant

In the data presented in table – 3, the two factors ANOVA for repeated measures shows that there was significant difference in caregiver's burden score. F test showed that the significant difference after intervention of STM (F=383.12, P<0.001) was in the experimental group compared to the control group (F=16.68, P<0.001).

Table - 4: Comparison of caregiver's burden scores within and between experimental and control groups through Bonferroni comparison post hoc test to assess the effectiveness of STM on homecare of children with intellectual disability among primary caregivers.

N=(60+60=120)

Observations		Experimental group			Control group		
		Mean Difference	SE	P-value	Mean difference	SE	P-Value
Pretest B ₁	Post-test I B ₂	23.617	1.238	<0.001	1.083	0.220	0.001
	Post-test II B ₃	24.933	1.194	<0.001	1.400	0.279	0.001
	Post-test III B ₄	25.433	1.211	<0.001	1.683	0.393	0.001

*-P<0.05, significant and **-P<0.01 & ***-P<0.001, highly significant

The post hoc Bonferroni test presented in table - 4 shows that there was significant difference in caregiver's burden scores from pre-test to consequent post-test both in the experimental and control groups (P<0.001). Mean difference was from 23.617 to 25.433 in the experimental group and from 1.083 to 1.683 in the control group. The post hoc Bonferroni test showed the difference between pre-test and consequent post-test was not by chance and it was highly significant between the consecutive assessments. However, there was no significant difference compared to the control group.

These findings are supported by a study done by Arpana Jadhav (2013) regarding caregiver's burden of mentally challenged children. It revealed that caregivers of mentally challenged children encounter different problems like feeling of burden in care giving leads to stress and demands of daily care, lack of leisure time, emotional disturbances such as worries, frustrations, sadness, irritability and relationship problems between family members. In addition, there is stigmatisation, social embarrassment and financial implication. The planned teaching had significantly brought out their reduction in the burden of caregivers of mentally challenged children. Sachin S and Suresh V, (2014), did a descriptive study to assess the burden among family caregivers of mentally ill clients in Gujarat. By non probability convenient sampling method, 60 family caregivers were identified with quantitative research approach. Caregiver's burden scale with 30 items was used to collect the data from the family caregivers. The result revealed that 27 (45%) of family caregivers had mild burden, 8 (13.3%) of family caregivers had moderate burden, 9 (15%) of family caregivers had severe burden and 16 (26.7%) of family caregivers had expressed no burden at all.

CONCLUSION

The findings of the present study revealed that on comparison, the post-tests caregiver's burden scores were significantly lower than the pre-test caregiver's burden score. This indicates that the structured teaching module (STM) on homecare of children with intellectual disability was effective in reducing caregiver's burden of primary caregivers. The study identified that, almost all the primary caregivers felt sever burden before implementation of structured teaching module regarding homecare children with intellectual disability. Hence structured teaching module on homecare of intellectually disabled children for primary caregivers will be helpful in reducing the caregiver's burden.

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